

<p style="text-align: center;"><b>AB 1648 (Pavley)</b> <b>Reflex Sympathetic Dystrophy (RSD/CRPS)</b> <b>Principal Co-authors: Senators Escutia and Soto</b> <b>Coauthors: Assemblymembers Chan, Dymally, Goldberg, Hancock, Oropeza, and Wolk</b> <b>Senators Figueroa and Kuehl</b></p>
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**Purpose:**

Create awareness of the causes, symptoms, and treatments of Reflex Sympathetic Dystrophy (RSD), to the medical profession and the public; provide funding for private and public research.

**Problem:**

Reflex Sympathetic Dystrophy (RSD) also known as Complex Regional Pain Syndrome (CRPS) can affect people of all ages, however men and women between the ages of 40-60 years old are most likely to fall ill with the disease. It is estimated that RSD affects anywhere from 1.5 million to 6 million people in the United States—exceeding those with breast cancer, HIV/AIDS and multiple sclerosis combined.

RSD/CRPS is a multi-symptom, multi-system, syndrome usually affecting one or more extremities, but may affect virtually any part of the body. RSD is usually the result of an injury of an extremity, a broken bone, a sprain, surgery, or a major trauma. There is no test to diagnose whether one has RSD, but rather a series of tests one must go through to rule out other diseases. There is also no cure for RSD. Moreover, early diagnosis is the most efficient way of handling and controlling the disease. If left untreated, RSD will spread throughout the body and cause complete paralysis.

Although RSD was discovered 125 years ago, it has not gained the prestige other nervous disorders have. Therefore, many doctors are not aware of it. Through education, outreach and research both the public and medical community will become aware of RSD, its symptoms, early diagnosis, and means of controlling it.

**Current Law:**

There is currently no California law pertaining to RSD. However other states (New Jersey, New York, Pennsylvania and Illinois), have taken great strides to make their citizens aware of this disease through research and education legislation.

**Background:**

RSD/CRPS is an injury to a nerve or soft tissue (e.g. broken bone) that does not follow the normal healing path. The development of RSD/CRPS does depend on the magnitude of the injury. The injury may be so slight that the patient may not recall ever being hurt (e.g. a sliver in the finger can trigger the disease). For reasons not understood, the sympathetic nervous system seems to assume an abnormal function after an injury.

There is a natural tendency to rush to the diagnosis of RSD/CRPS with minimal objective findings because early diagnosis is critical. If undiagnosed and untreated, RSD/CRPS can spread to all extremities, making the rehabilitation process a much more difficult one.

If diagnosed early, practitioners can use mobilization of the affected extremity (physical therapy) and sympathetic nerve blocks to cure or mitigate the disease. There are no studies showing that RSD/CRPS affects the patient's life span. However, due to the unbearable pain of many RSD/CRPS patients, it is called the "suicide disease" because so many patients with it kill themselves. Some describe the pain as "pouring gasoline over oneself and light oneself on fire."

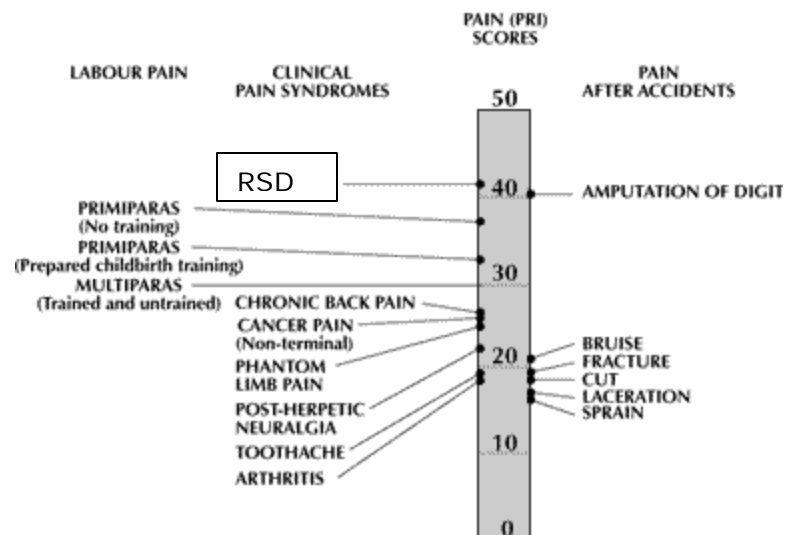
If left untreated RSD/CRPS can lead to long-term financial consequences due to permanent deformities and chronic pain. At an advanced state of illness, patients may have significant psychological and psychiatric problem, they may have dependency on narcotics and may be completely incapacitated by the disease.

### Making the Diagnosis of RSD/CRPS

The diagnosis of RSD/CRPS can be made in the following context. A history of trauma to the affected area associated with pain that is disproportionate to the inciting event plus one or more of the following:

- Abnormal function of the sympathetic nervous system.
- Swelling.
- Movement disorder.
- Changes in tissue growth.

Thus patients do not have to meet all of the clinical manifestations listed above to make the diagnosis of RSD/CRPS. The new CRPS classification system acknowledges this fact by stating that some patients with RSD/CRPS may have a third type of CRPS by categorizing it as "otherwise not specified". There seems to be a small group of patients whose pain following trauma resolves over time, leaving the patient with a movement disorder. The pain and symptoms of RSD/CRPS may exceed both the magnitude and duration of symptoms expected from the normal healing process expected from the inciting event. Similarly, the RSD/CRPS diagnosis is precluded by the existence of known pathology that can be explained by the observed symptoms and degree of pain. There are "grades" of this syndrome described in the literature with symptoms ranging from minor to severe.



**Comments:**

To often many men, women and children go undiagnosed and suffer great pain and agony due to the affects of RSD. At times the pain becomes so unbearable these victims resort to taking their lives, hence labeling it as the “suicide disease”. By enacting this legislation, Californians can rest assured that their doctors will become more aware of this devastating disease, as will they.

**AB 1648:**

This bill requires the Department of Health Services to create a program for research and education on the debilitating disease called Reflex Sympathetic Dystrophy (RSD). In order for this program to be enacted, outside funding must be present. No general fund monies or other state money will fund this program.

**Support:**

American Chronic Pain Association (Co-sponsor)  
American Pain Foundation  
American RSD Hope (Co-sponsor)  
California Applicants’ Attorneys Association  
Cedars Sinai Pain Center  
For Grace (Co-sponsor)  
Reflex Sympathetic Dystrophy Syndrome Association  
Southern CA Cancer Pain Initiative (Co-sponsor)

**Oppose:**

None on file.

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